

# There Is a Mismatch Between the Medicare Benefit Package and the Preferences of Patients With Cancer and Their Caregivers

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## ABSTRACT

### Purpose

To identify insured services that are most important to Medicare beneficiaries with cancer and their family caregivers when coverage is limited.

### Methods

A total of 440 participants (patients,  $n = 246$ ; caregivers,  $n = 194$ ) were enrolled onto the CHAT (Choosing Health Plans All Together) study from August 2010 to March 2013. The exercise elicited preferences about what benefits Medicare should cover for patients with cancer in their last 6 months of life. Facilitated sessions lasted 2.5 hours, included 8 to 10 participants, and focused on choices about Medicare health benefits within the context of a resource-constrained environment.

### Results

Six of 15 benefit categories were selected by  $> 80\%$  of participants: cancer care, prescription drugs, primary care, home care, palliative care, and nursing home coverage. Only 12% of participants chose the maximum level of cancer benefits, a level of care commonly financed in the Medicare program. Between 40% and 50% of participants chose benefits not currently covered by Medicare: unrestricted cash, concurrent palliative care, and home-based long-term care. Nearly one in five participants picked some level of each of these three benefit categories and allocated on average 30% of their resources toward them.

### Conclusion

The mismatch between covered benefits and participant preferences shows that addressing quality of life and the financial burden of care is a priority for a substantial subset of patients with cancer in the Medicare program. Patient and caregiver preferences can be elicited, and the choices they express could suggest potential for Medicare benefit package reform and flexibility.

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## INTRODUCTION

The Medicare program has paid for “reasonable and necessary” care since its inception in 1965 and, in doing so, has provided a set of medical entitlements for beneficiaries that creates a de facto standard of care for private insurers as well.<sup>1,2</sup> Beneficiaries, their adult children, and health care providers all have incentives to ensure that Medicare coverage options remain broad. Meanwhile, Medicare is a major focus of efforts to constrain the federal budget,<sup>3</sup> regardless of slowing rates of health care inflation.<sup>4</sup> Maintaining expansive Medicare benefits and maximum choice is in direct conflict with cost control.

Resolving this tension is a major public policy dilemma that affects every American in one or more ways—as a taxpayer, patient, provider, family member, or future patient.<sup>5</sup> Cancer care is likely to be

among the most contentious clinical areas because of the following: common diagnosis of cancer among Medicare beneficiaries; rapidly expanding understanding of cancer biology and treatment alternatives without clarity of impact on outcomes; concomitant accelerating costs; public sense of urgency to ensure a full portfolio of treatments; and increasing clinical and personal needs at the end of life.<sup>6</sup> The Institute of Medicine (IOM) has concluded that cancer care is not as patient centered or evidence based as such an important area ought to be and that we can and should improve value.<sup>7</sup>

Evidence can, and should, direct policy development. The public has shown that it can offer balanced advice on the tradeoffs in health care benefit choices for public and private insurance, when options are framed in guided individual and group settings.<sup>8</sup> In this study, we asked Medicare

**Table 1.** Sociodemographic Characteristics and Health Status of Participating Patients and Caregivers

Characteristic	All Participants (N = 440)		Patients (n = 246)		Caregivers (n = 194)	
	No.	%	No.	%	No.	%
Age, years						
Mean	69		73		64	
SD	10.0		7.1		10.7	
Female sex	258	58.8	120	48.8	138	71.5
Race						
Native American	8	1.8	6	2.4	2	1.0
African American	131	29.5	64	26.0	67	34.5
White	289	65.7	169	68.7	120	61.8
Other	7	1.6	4	1.6	3	1.5
Unknown	5	1.1	3	1.2	2	1.0
Ethnicity						
Hispanic or Latino	3	0.1	2	0.1	1	0.1
Not Hispanic or Latino	386	87.7	219	84.0	167	86.1
Unknown	51	11.6	25	10.2	26	13.4
Marital status						
Married or living with partner	322	73.3	171	69.5	151	77.8
Single or never married	15	3.4	6	2.4	9	4.6
Widowed, divorced, or separated	101	23.0	69	28.0	32	16.5
Unknown	2	0.1	0	0.0	2	1.0
Relation to patient						
Spouse					99	51.0
Sibling					8	4.1
Child					36	18.6
Other					39	20.1
Unknown					12	6.2
Educational attainment						
< High school	29	6.6	20	8.2	9	4.6
High school graduate or GED	88	20.1	43	17.6	45	23.2
Some college	135	30.9	66	27.0	69	35.6
≥ College graduate	184	42.1	114	46.7	70	36.1
Unknown	4	0.9	3	0.4	1	0.1
Household income, \$						
< 20,000	66	15.1	39	15.9	27	13.9
20,000 to 39,900	81	18.5	49	20.0	32	16.5
40,000 to 59,900	94	21.5	48	19.6	46	23.7
60,000 to 79,900	83	18.9	49	20.0	34	17.5
≥ 80,000	107	24.4	57	23.3	50	25.8
Not answered	9	1.8	4	1.6	5	2.6
Health status*						
Poor	8	1.8	8	3.3	0	0.0
Fair	66	15.0	50	20.3	16	8.0
Good	168	38.3	93	37.8	75	38.7
Very good	143	32.6	70	28.5	73	37.6
Excellent	53	12.1	24	9.8	29	14.9
Not answered	2	0.1	1	0.4	1	0.1
Advanced-stage disease						
Yes			96	39		
No			134	54		
Unknown†			16	7		
Cancer type						
Breast			42	17.1		
Prostate			39	15.9		
Lung			35	14.2		
Colon or colorectal			15	6.1		
Bladder			11	4.5		
Lymphoma			10	4.1		

(continued in next column)

**Table 1.** Sociodemographic Characteristics and Health Status of Participating Patients and Caregivers (continued)

Characteristic	All Participants (N = 440)		Patients (n = 246)		Caregivers (n = 194)	
	No.	%	No.	%	No.	%
Pancreatic					10	4.1
Ovarian					8	3.3
Head and neck					7	2.8
Leukemia					7	2.8
Multiple myeloma					6	2.4
Endometrial					4	1.6
Brain					3	1.2
Kidney					3	1.2
Skin					7	2.8
Other					26	10.6
Unknown					13	5.3
Out-of-pocket payments in past 12 months, \$						
0					11	4.5
< 500					20	8.1
500 to < 2,000					55	22.4
≥ 2,000					124	50.4
Unknown					36	14.6

NOTE. Percentages may not total 100 because of rounding.

Abbreviations: GED, general educational development; SD, standard deviation.

\*Health status represents patient response to question: "In general, would you say your health is...?"

†Thirteen patients had missing chart data. Self-reported cancer types for these patients included breast, lymphoma, prostate, other, unknown (each n = 2); leukemia, lung, and pancreas (each n = 1).

beneficiaries with cancer and their caregivers (typically spouse or adult child) to choose which benefits Medicare should cover for people with cancer in the last 6 months of life, when choices were limited by resource constraints.

## METHODS

We adapted a participatory decision-making process using a game-based approach called the Choosing Health Plans All Together (CHAT) methodology to cancer.<sup>8</sup> CHAT is designed to elicit informed preferences of individuals and groups by providing information and facilitating deliberation. Both individual and consensus choices regarding what services should be covered by Medicare were measured. The Duke Medical Center Institutional Review Board and the Office of Human Subjects Research Protection at the National Institutes of Health Clinical Center approved this project. Informed consent was obtained from each participant. Trained personnel conducted the CHAT sessions. Snacks were provided. On completion of the exercise, participants received a payment of \$75.

### Participants

Participants were recruited through the Duke University Health System, community facilities (eg, retirement communities), and cancer-related organizations in central North Carolina. Eligible participants were Medicare beneficiaries (age ≥ 65 years) with active or previously treated cancer (past 5 years) and adult family caregivers. Most caregivers were spouses (n = 99; 51.0%), but they also included adult children (n = 36; 18.6%), siblings (n = 8; 4.1%), and other adults (n = 39; 20.1%). Two participants were excluded because their CHAT session only included one person, and a third individual did not complete the study. The final study sample (N = 440) included 246 patients and 194 caregivers (Table 1).

Patient cancer diagnosis was ascertained from medical record reviews conducted by a study author and oncologist (L.J.H.), who consulted with another author oncologist (S.Y.Z.) to reach consensus on difficult cases. We could not obtain medical records for 13 patients; their self-reported diagnoses were used. We also categorized patient cancer stage as a binary variable: advanced ( $n = 96$ ; 39%) versus nonadvanced cancer ( $n = 134$ ; 54%); stage was unknown for 16 patients because of incomplete information. Target group size for CHAT sessions was eight to 10 participants, but smaller groups were held, usually because of last-minute cancellations for reasons such as adverse effects of treatment. Sessions lasted approximately 2.5 hours and consisted of the following: a pre-CHAT questionnaire; four rounds of the CHAT exercise, in which participants made decisions about what benefits Medicare should cover; and a post-CHAT questionnaire.<sup>7</sup> The structure of the CHAT session was as follows: in round one, after being oriented to the exercise and given educational materials about benefit categories, participants made individual coverage choices; in round two, a small group discussion (three to four persons) yielded a small group consensus choice; in round three, a full group discussion yielded a full group consensus choice; and finally, in round four, individual benefit choices were again made. This article focuses on the individual choices in round one.

### Measurements

Fifteen benefit categories (description provided in Appendix, online only) were offered to participants, including benefits currently covered by Medicare (eg, cancer therapy, primary care) as well as benefits not currently covered by Medicare (eg, cash payments, home-based long-term care [LTC], concurrent palliative care). Participants were given 50 stickers with which they could select their benefit choices on a circular game board. A total of 87 stickers were required to select the maximum level of care for each benefit, so participants faced a substantial resource constraint. The relative cost of each benefit—designated in terms of number of stickers—was determined as described in the following section.

### Procedure for Developing CHAT Benefit Design

We included a range of options in the CHAT exercise that we believe reflect the full dimension of services from which patients with advanced cancer might possibly benefit. They cover domains that range from cancer treatments and management of treatment complications to preservation of function, psychosocial support, logistical support, and financial support. Categories were selected based on published data about the health care needs of people with advanced life-limiting illness<sup>9,10</sup> (description provided in Appendix, online only).

We estimated the cost of Medicare-financed care in the last 6 months of life for a claims-based cancer death cohort of Medicare decedents age  $\geq 65$  years (5% claims sample; 2007), using the amount paid by Medicare. We identified decedents who had at least one hospitalization in their last 6 months of life with a primary cancer diagnosis (signified by one International Classification of Diseases [ninth revision] Clinical Modification code in the following ranges: 140.xx-165.xx, 170.xx, 171.xx, 172.xx, 174.xx, 175.xx, 176.xx, 179.xx-195.xx, 200.xx-208.xx, and 236.6x).

Our goal was to produce a cost estimate of the care provided in the last 6 months of life to determine the dollar value that each CHAT participant was given to allocate in choosing benefits. To arrive at this approximate cost, we added the mean Medicare payment for hospitalization (\$20,579), skilled nursing facility (\$1,962), hospice (\$3,190), home health (\$930), and physician plus durable medical equipment (\$7,193) for members of the cancer death cohort identified in Medicare claims in 2007 ( $N = 327,457$ ). Each mean value describes the subset of the cancer decedent cohort using this type of care during their last 6 months of life. We added these mean values to arrive at an estimate of \$33,854, which we inflated by approximately 5% to obtain a round total of \$35,000. This \$35,000 in 2010 dollars provides a plausible average estimate of the amount of Medicare-financed health care that was used by cancer decedents in their last 6 months of life.

The \$35,000 amount was divided into 50 units, represented by stickers; each sticker was thus worth approximately \$700. Differing benefits and levels of intensity were assigned relative costs based on the Medicare data analysis of care now covered in the Medicare benefit package. For the cost of options that do not exist among current Medicare benefits, such as discretionary cash or ex-

panded LTC, we used internal Duke University cost estimates as well as local market estimates to estimate the relative cost of these benefits. The maximum level of all benefit categories would require 87 stickers, for an estimated cost of \$60,900 (number of stickers assigned to each benefit provided in Appendix, online only).

Although the benefit options were broadly based on Medicare and other costs, monetary value of benefit options in the exercise was not explicitly communicated in dollar amounts but rather was conveyed by the number of stickers required to select an option. Participants were told they only had 50 stickers and could not choose everything.

### Analysis

The benefit choices of study participants from round one were described and compared using basic statistics, including Spearman correlation coefficients;  $\chi^2$  tests of proportions were used to test for strength of relationships between participant demographic characteristics and their choices (Appendix Table A1, online only). We compared round one and round four benefit choices for selected benefit categories to determine if selection of noncovered benefits was a stable choice and further investigated the subset of participants who selected each of three key noncovered benefits using exploratory multivariable stepwise proportional odds<sup>11</sup> models.  $P$  values  $< .05$  were considered statistically significant. All analyses were conducted using SAS software (version 9.3; Cary, NC).

## RESULTS

### Participant Characteristics

Participants ( $N = 440$  total; patients,  $n = 246$ ; caregivers,  $n = 194$ ) had diverse socioeconomic backgrounds and cancer profiles consistent with patients in North Carolina. The most prevalent cancers were breast (17%), lung (15%), and prostate (16%); 96 patients (39%) had advanced cancer, and 134 (54%) did not, whereas the cancer status of 16 patients (7%) was unknown. Patients were age 73 years ( $\pm$  standard deviation [SD] of 7 years) on average; caregivers were younger (age  $64 \pm$  SD of 11 years; Table 1). Half of the patients (49%) were women, and caregivers were mostly women (72%). One quarter of patients (26%) and 35% of caregivers were African American. Focusing on the full sample, there was wide variation in participant education and income. One quarter (27%) had  $\leq$  a high school degree, but 42% had  $\geq$  a college degree. One third of participants (34%) had annual household incomes  $< \$40,000$ , and half of patients (50%) reported spending  $\geq \$2,000$  out of pocket on medical care in the prior year.

### Individual Benefit-Level Choices

CHAT round one measured participant preferences for which benefits Medicare should cover for patients with cancer near the end of life, before the patients and caregivers engaged the views of others in a similar situation. Not surprisingly, nearly all (except one participant) chose some level of cancer treatment (Table 2), although they invested differentially in such care, with 40% choosing the intermediate benefit level, requiring 14 of 50 stickers, and 42% selecting the benefit level labeled high, requiring 21 of 50 stickers. Only 6% chose the basic level of cancer treatment (seven of 50 stickers), whereas 12% chose the most advanced level of cancer treatment, requiring nearly all available stickers (42 of 50).

Round one choices for each benefit type are listed in Table 2. At least eight of 10 participants chose some level of coverage for five other benefit types in addition to their near-universal choice of some level of cancer care. These benefit categories included coverage of prescription drugs (not including cancer therapy drugs), which was chosen by nearly all participants (95%); coverage of primary care (90% choosing

**Table 2.** Frequency of Participants Electing Specific Benefits in Round One

Benefit Category	Not Selected		Basic		Intermediate		High		Advanced	
	No.	%	No.	%	No.	%	No.	%	No.	%
Treatment for cancer	1	0.2	28	6.4	174	39.5	186	42.3	51	11.6
Primary care	44	10.0	396	90.0						
Palliative care	80	18.2	163	37.0	127	28.9	70	15.9		
Other medical care	102	23.2	338	76.8						
Nursing facility	87	19.8	132	30.0	221	50.2				
House calls	218	49.5	222	50.5						
Home improvement	162	36.9	156	35.5	66	15.0	55	12.5		
Home care	64	14.5	146	33.2	119	27.0	111	25.2		
Emotional	182	41.4	258	58.6						
Drugs	22	5.0	90	20.5	328	74.5				
Dental/vision	136	30.9	304	69.1						
Cosmetic care	204	46.4	236	53.6						
Complementary medicine	273	62.0	167	38.0						
Cash	238	54.1	124	28.2	43	9.8	35	8.0		
Advice	207	47.0	233	53.0						

NOTE. Blank areas represent choices that were not offered; benefit categories had between two (yes v no) and five levels of choice, in case of cancer treatment: none, basic, intermediate, high, and advanced (labels provided to participants).

only level offered), home care (85% choosing one of three levels offered), palliative care (82% choosing one of three levels offered), and coverage of care in a nursing facility (80% choosing one of two levels offered) accounted for the rest. There were no differences between the benefit choices of patients and caregivers for any benefit categories (smallest *P* value for comparisons: *P* = .11).

We highlight participant preferences for three core Medicare benefits (cancer care, primary care, and prescription drugs), as well as their preferences for three types of benefits that are not currently covered by the Medicare program: unrestricted cash, concurrent palliative care, and home-based LTC (Table 3). Virtually all persons chose some level of the three core services, as would be expected, but a substantial proportion of participants also chose benefits that are not currently covered by Medicare: 202 (46%) choose some level of unrestricted cash; 197 (45%) selected concurrent palliative care, a level of care beyond the current Medicare hospice benefit; and slightly more than half (*n* = 230; 52%) chose home-based LTC services designed to address disability.

Selection of noncovered benefits was fairly stable, whether measured at round one or at round four, after participants had a chance to discuss their choices during the CHAT exercise. Seventy-seven participants (18%) selected each of the three currently uncovered benefit categories in round one, investing a mean of 15.5 of their 50 stickers (SD, 4.27; range, 11 to 24) on these uncovered benefits. Stepwise logistic regression using the variables listed in Table 1 showed that the only significant predictor of choosing all three noncovered benefits was race, with African Americans more likely to do so than whites (odds ratio, 1.91; 95% CI, 1.14 to 3.23). In similar models predicting all round one benefit choices, the only significant results for the six highlighted benefits in Table 3 were for selection of the cash benefit. Those with lower incomes and African American race were more likely to pick cash benefits; these analyses are exploratory.

## DISCUSSION

There is an escalating tension between policy and the day-to-day provision of health care; a key theme of the recent IOM report on cancer care is

that our system is in crisis.<sup>7</sup> The situation is particularly acute in Medicare, where we must align benefits with patient preferences while also controlling costs in a politically charged atmosphere. Ideally, both public and personal preferences are taken into account in setting Medicare policy. The most important finding in this study is the gap between participant preferences and the benefits that Medicare currently covers.

The gap between covered benefits and preferences points toward a subset of patients and caregivers valuing quality of life broadly defined over medical care only. Approximately half of our respondents chose to allocate finite resources toward one of three benefits not now covered by Medicare: unrestricted cash, concurrent palliative care, and home-based LTC. Given the nature of the CHAT exercise, these choices came at the expense of reduced medical care such as the most sophisticated (and expensive) cancer treatment. Furthermore, nearly one in five participants choose some level of each of these three benefits, allocating an average of 15.5 of 50 stickers toward these benefits and away from something else; by comparison, moving from the intermediate to high level of cancer care took just seven stickers.

The identified benefit mismatch could be viewed as both a problem and an opportunity. As Etheredge<sup>6</sup> has described, getting a handle on costs and benefit provision will be more difficult in cancer than in other diseases because of the myriad therapeutic choices. This study demonstrates that evidence can be elicited directly from patients and caregivers—the people most affected—who tended to agree on their choices, mirroring past work showing their agreement on important factors at the end of life.<sup>9,10</sup> Their decision to choose cash, home-based LTC coverage, and concurrent palliative care is not imprudent, given work demonstrating the financial burden of cancer care and the difficulty that families have in addressing the disability and symptom burden that increases as cancer advances.<sup>12–17</sup> Furthermore, these preference mismatches were stable (before and after detailed discussions between participants that are not reported here), so they do not seem to represent whimsical choices. Although a stark constraint such as the one we imposed during our study is unlikely in the Medicare program, our results suggest patients and caregivers are prepared to



**Table 3.** Participant Preferences for Selected Benefit Categories

Benefit Category	Round One		Round Four		P
	No.	%	No.	%	
Core Benefits Covered by Medicare					
Treatment for cancer					.045
Not selected	1	0.2	1	0.2	
Basic	28	6.4	15	3.4	
Intermediate	174	39.5	172	39.2	
High	186	42.3	217	49.4	
Advanced	51	11.6	34	7.7	
Primary care					.240
Not selected	44	10.0	34	7.7	
Basic	396	90.0	405	92.3	
Drugs					.013
Not selected	22	5.0	10	2.3	
Basic	90	20.5	69	15.7	
Intermediate	328	74.5	360	82.0	
Benefits Not Covered by Medicare					
Cash					.312
Not selected	238	54.1	249	56.7	
Basic	124	28.2	114	26.0	
Intermediate	43	9.8	52	11.8	
High	35	8.0	24	5.5	
Home care					.111
Not selected	64	14.5	53	12.1	
Basic	146	33.2	163	37.1	
Intermediate	119	27.0	136	31.0	
High	111	25.2	87	19.8	
Palliative care					.013
Not selected	80	18.2	63	14.4	
Basic	163	37.0	185	42.1	
Intermediate	127	28.9	147	33.5	
High	70	15.9	44	10.0	

make difficult tradeoffs, pointing toward the option of allowing flexibility in how patients and families choose to expend resources. This would be a radical departure from the current policy milieu, but those living with cancer may be the ones most ready to make such difficult choices and tradeoffs, echoing the IOM cancer report.<sup>7</sup>

Patients and caregivers in our study are signaling an interest in expanding benefits that focus on improving quality of life for those with cancer, even as a resource constraint is imposed. Even though all participants were either patients with cancer or their caregivers, few participants (round one, 12%; round four, 8%) chose the maximum level of cancer treatment offered in the study, even though this level of treatment is commonly provided by the current Medicare benefit package definition of reasonable and necessary—at great expense to Medicare and society. The willingness to allocate finite resources toward home-based LTC and concurrent palliative care shows these uncovered services address strongly felt needs for many patients and caregivers.

This study is limited most obviously because it is a simulation. Patient and caregiver endorsements do not necessarily reflect the decisions they would make in real life, and the options we offered presented stark choices, whereas the Medicare program does not. However, the kind of methodology that we used—involving public deliberation about priority setting—has been endorsed by the IOM and others for use in getting public input about the design of basic

insurance benefits.<sup>13,14</sup> The CHAT method has been used extensively to ascertain the insurance coverage preferences of healthy individuals. Our study involving patients with cancer, cancer survivors, and family members has advantages over these earlier studies with healthy individuals, in that our participants were probably less naive than those participating in previous CHAT exercises. Our findings seem to echo the views of patients with cancer, as reflected in published findings that some financially disadvantaged patients with cancer have opted to receive less than the most aggressive cancer care.<sup>18</sup>

Second, our participants were mostly from central North Carolina. The racial and economic diversity of our sample is a strength and allows us to show that African Americans are more likely to allocate resources toward the noncovered benefits. Certainly, replication in other geographic areas and with individuals who have experienced other illnesses is warranted. Finally, we asked participants to imagine the benefits most appropriate for patients with cancer in the last 6 months of life, but all of these patients with cancer were not in fact in that period.

Patients with cancer and their caregivers are key stakeholders, but they are not the only ones with a stake in determining those benefits that Medicare will cover and how. The most challenging application of this study is to determine whether and how the thoughtful and reasoned discussion of care options and tradeoffs given a resource constraint that we observed can be simulated nationally, not only among Medicare beneficiaries (both ill and well) but among providers and younger tax payers as well, who will be Medicare beneficiaries in the future and who will bear the burden of financing the care of current beneficiaries.

#### AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

*Although all authors completed the disclosure declaration, the following author(s) and/or an author's immediate family member(s) indicated a financial or other interest that is relevant to the subject matter under consideration in this article. Certain relationships marked with a "U" are those for which no compensation was received; those relationships marked with a "C" were compensated. For a detailed description of the disclosure categories, or for more information about ASCO's conflict of interest policy, please refer to the Author Disclosure Declaration and the Disclosures of Potential Conflicts of Interest section in Information for Contributors.*

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## REFERENCES

1. Neumann PJ, Chambers JD: Medicare's enduring struggle to define "reasonable and necessary" care. *N Engl J Med* 367:1775-1777, 2012
2. Taylor DH Jr: Medicare as insurance innovator: The case of hospice. *Am J Hosp Palliat Care* 30:556-557, 2012
3. Congressional Budget Office: Updated budget projections: Fiscal years 2013 to 2023. <http://www.cbo.gov/sites/default/files/cbofiles/attachments/44172-Baseline2.pdf>
4. Fuchs VR: The gross domestic product and health care spending. *N Engl J Med* 369:107-109, 2013
5. Brody H: From an ethics of rationing to an ethics of waste avoidance. *N Engl J Med* 366:1949-1951, 2012
6. Etheredge LM: Medicare's future: Cancer care. *Health Aff (Millwood)* 28:148-159, 2009
7. Institute of Medicine: Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis. Washington, DC, National Academies Press, 2013
8. Danis M, Ginsburg M, Goold S: Experience in the United States with public deliberation about health insurance benefits using the small group decision exercise, CHAT. *J Ambul Care Manage* 33:205-214, 2010
9. Steinhauser KE, Christakis NA, Clipp EC, et al: Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 284:2476-2482, 2000
10. Emanuel EJ, Fairclough DL, Slutsman J, et al: Understanding economic and other burdens of terminal illness: The experience of patients and their caregivers. *Ann Intern Med* 132:451-459, 2000
11. Peterson B, Harrell FE Jr: Partial proportional odds models for ordinal response variables. *Appl Stat* 39:205-217, 1990
12. Schwartz K, Claxton G, Martin K, et al: Spending to Survive: Cancer Patients Confront Holes in the Health Insurance System. <http://www.cancer.org/acs/groups/content/@corporatecommunications/documents/document/acsq-017518.pdf>
13. Carmen KL, Dardess P, Maurer M, et al: Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Aff (Millwood)* 32:223-231, 2013
14. Ulmer C, Ball J, McGlynn E, et al (eds): *Essential Health Benefits: Balancing Coverage and Cost*. Washington, DC, National Academies Press, 2012
15. Zafar SY, Peppercorn JM, Schrag D, et al: The financial toxicity of cancer treatment: A pilot study assessing out-of-pocket expenses and the insured cancer patient's experience. *Oncologist* 18:381-290, 2013
16. Kim Y, Schulz R: Family caregivers' strains: Comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *J Aging Health* 20:483-503, 2008
17. Girgis A, Abernethy AP, Currow DC: Caring at the end of life: Do cancer caregivers differ from other caregivers? *BMJ Support Palliat Care* [epub ahead of print on January 22, 2014]
18. Weaver KE, Rowland JH, Bellizzi KM, et al: Forgoing medical care because of cost: Assessing disparities in healthcare access among cancer survivors living in the United States. *Cancer* 16:3496-3504, 2010



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### **Appendix**

#### **Description of Benefit Options**

##### **Advice**

Insures that a person receives help with writing a living will or other legal documents so the family and physician will know what to do if the patient is unable to make decisions. A person may also get help with planning to distribute personal property. This may include preparing a will and setting up trusts to transfer one's assets. This can reduce taxes after death.

*Basic (one sticker).* A person receives the services as described.

##### **Cash**

Cash is provided for patients to spend as they need. For example, a person can pay rent or mortgage or for medical care, medicines, food, travel, or homemaker services.

*Basic (three stickers).* A person receives \$360 each month.

*Intermediate (seven stickers).* A person receives \$840 each month.

*High (10 stickers).* A person receives \$1200 each month.

##### **Complementary Medicine**

This provides alternative services. This includes acupuncture for pain as well as chiropractic services, massage treatments, and relaxation treatments. It also includes visits to a spa or retreat.

*Basic (one sticker).* A person receives these treatments and services.

##### **Cosmetic Care**

This provides services to help patients with cancer recover how they look and look their best.

*Basic (one sticker).* A person receives needed surgery, wigs, prostheses, scar treatment and scar repair, and other treatments.

##### **Dental/Vision Services**

This helps patients living with cancer pay for services to prevent problems with their teeth or eyes. It also pays for tests and treatments for dental and visual problems. This includes contact lenses and spectacles.

*Basic (one sticker).* A person receives regular cleanings and x-rays, has cavities filled and bad teeth extracted, receives complete dental care including crowns, receives an eye examination every 2 years, and receives lenses and frames if needed.

##### **Drugs**

This provides help for people living with cancer to pay for non-cancer-related prescribed medicines. Cancer medicines would be provided under the Treatment for Cancer category.

*Basic (two stickers).* A person has part of his or her outpatient prescribed drugs paid for, as in Medicare Part D.

*Intermediate (three stickers).* A person has all out-patient prescribed drugs paid for. This covers an insurance gap and is called doughnut hole coverage.

##### **Emotional Support**

This provides support and counseling, support groups, and pastoral care. This also covers support for family members during treatment and after a patient with cancer dies. Psychosocial services can be provided to patients and family members, either alone or together. The goal of these services is to help patients and family members cope with the effects of cancer on the patient and family.

*Basic (one sticker).* A team including nurses and social workers provides support. Grief counselors and pastoral counselors also provide for psychological needs of patients and caregivers. The team also gives information about and referrals to religious and spiritual caregivers for patients and families.

##### **Home Care**

This covers medical services at home by licensed health care workers. This can involve nursing and provision of drugs and other treatments. This can also include intravenous and aerosol treatments, tube feeding, and other medical treatments, as well as health aide services to help with bathing, toileting, feeding, and other personal care.

*Basic (two stickers).* All in-home care is paid. Each month, a patient receives four visits from a nurse and daily care from a nurse's aide for 1 hour.

*Intermediate (three stickers).* All in-home care is paid. Each month, a patient receives eight visits from a nurse and daily care from a nurses' aide for 2.5 hours.

*High (five stickers).* All in-home care is paid. Each month, a patient receives 15 visits from a nurse and daily care from a nurses' aide for 2.5 hours.

### **Home Improvements/Equipment**

This provides items such as wheelchairs, walkers, and raised toilet seats to assist persons with limited ability to move on their own. It can also provide home remodeling, including ramps, stability bars, and lifts to assist patients with moving in their home and to help them get in and out of bed.

*Basic (one sticker).* A person receives needed equipment for use at home, including walkers, canes, wheelchairs, and commodes.

*Intermediate (two stickers).* Includes the Basic equipment, plus bathroom and/or living area remodeling to assist with activities of daily living.

*High (three stickers).* Includes the Basic and Intermediate services, plus outside improvements to a person's residence.

### **House Calls**

This ensures that a medical provider such as a physician, nurse, or physician assistant can come to the patient's home to diagnose any medical problem or complaint.

*Basic (two stickers).* A person receives this care if needed.

### **Nursing Facility**

Pays for a skilled nursing home or rehabilitation center. This provides short-term skilled nursing care and related services for patients. This can include services to improve the function of injured, disabled, or sick persons. Such facilities provide all care needed by patients.

*Basic (two stickers).* A person receives help with daily needs and skilled care prescribed by physicians provided by nurses and certified nurse assistants.

*Intermediate (three stickers).* Includes Basic services, plus physical, occupational, and other therapies.

### **Other Medical Care**

This provides hospital care to address major health problems that may be unrelated to cancer. This may include heart surgery after a heart attack, hip or knee replacement to address mobility disability, or surgery to address a chronic back ailment. This covers services such as x-rays, laboratory tests, major surgery, and follow-up outpatient appointments.

*Basic (four stickers).* A person receives these treatments and care if he or she experiences any of these events.

### **Palliative Care**

This provides relief of pain, stress, and any other troubling symptoms of serious illness.

*Basic (three stickers).* Consists of standard inpatient and outpatient pain and symptom management, including symptoms from cancer treatment. A pain specialist becomes involved with a patient's care when symptoms appear. Hospice care is available if a decision is made by the patient to discontinue curative treatments.

*Intermediate (six stickers).* Consists of Basic treatment, plus coverage of occasional respite care so a patient can be cared for if his or her family needs a break from patient care. A pain specialist becomes involved at the beginning of the patient's illness to help the oncologist in designing a plan to assess and manage symptoms and adverse effects.

*High (nine stickers).* Consists of Basic and Intermediate treatments, plus a team of palliative care professionals. The whole team works together to look at the patient's values, preferences, and goals and the needs of the patient and family. The team addresses physical, social, spiritual, religious, existential, and cultural aspects of care. Provides a team who responds to the patient and family 24 hours a day, 7 days a week, throughout the course of treatment.

### **Primary Care**

This provides first-contact care to diagnose any sign, symptom, or health concern. This is the care provided by a patient's typical health care provider. This would cover treatment for illnesses that might be unrelated to cancer.

*Basic (two stickers).* A person receives office visits, outpatient services (noncancer), and preventive services.

### **Treatment for Cancer**

Cancer care is given to control a patient's cancer. It treats cancer symptoms and manages treatable medical problems that occur during cancer treatment.

*Basic (seven stickers).* Care aims to improve quality of life and ease pain. It has no effect on life expectancy.

*Intermediate (14 stickers).* Includes Basic treatment, plus more care aimed at improving quality of life and easing pain. It provides a small chance of prolonging life and includes proven cancer drugs. It also pays for routine care during a research study testing an experimental drug. There is some risk of treatment adverse effects. It is provided when a patient is expected to live 6 months.



*High/intermediate (21 stickers).* Includes Basic and Intermediate treatment, plus more aggressive care aimed at increasing length of life. Improved quality of life and reduced pain are expected. It includes proven cancer drugs regardless of cost and newer unproven drugs via clinical trials. There is a higher risk of treatment adverse effects. It is provided even when patient is expected to live 3 months and has declining function.

*Advanced (42 stickers).* Last-ditch care administered no matter how long a person is expected to live and how limited their function. Treatments are expensive. They have < 5% chance of success. They have more negative adverse effects that may include death. However, there is a small chance that these treatments may extend life. They may even lead to cure in rare cases.

**Table A1.** Association Between Demographic Variables and Round One Benefit Choices

Benefit Type	Sex*		Age†		Race‡		Health§		Education		Income¶		Advanced#	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Palliative care									1.33	1.10 to 1.60				
Primary care							1.96	1.17 to 3.28						
Other medical facilities													0.52	0.27 to 0.99
Nursing facilities											1.44	1.18 to 1.75	0.55	0.33 to 0.94
Home improvement			1.04	1.01 to 1.08										
Drugs	2.37	1.25 to 4.51	0.95	0.91 to 0.995										
Dental care							1.52	1.11 to 2.07						
Complementary medicine									1.29	1.03 to 1.60				
Cash					0.46	0.24 to 0.87					0.77	0.62 to 0.96		

NOTE. Multivariable stepwise proportional odds model performed on all benefit categories. Variables left in model after stepwise regression were associated with benefit choices. Blank cells represent demographic variables not significantly associated with benefit choice ( $P < .05$  indicates significance).  
Abbreviation: OR, odds ratio.  
\*Men more likely than women to allocate resources to drugs.  
†Older patients more likely to allocate more resources to home improvement; younger patients more likely to allocate more resources to drugs.  
‡Whites less likely to allocate resources to cash compared with African Americans.  
§Those reporting higher overall health allocated more resources to primary, other, and dental care.  
||As education increased, patient more likely to allocate more resources to palliative care and complementary medicine.  
¶As income increased, patient more likely to allocate more resources to nursing facilities and less likely to allocate resources to cash.  
#Patients diagnosed with advanced cancer less likely to allocate more resources to other medical or nursing facilities.